## APPENDIX 3­­­­­­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

# Information Sheet

# Exploring young adults’ experiences of growing up with a facial difference

My name is Samina Kiran Tariq and I am conducting this research as a student in the MSc Psychology (conversion) programme*]* at Manchester Metropolitan University, Manchester, United Kingdom.

# What is the study about?

The purpose of this study is to find out about the experiences of young adults who have grown up with a facial difference in the UK, focusing on the role that appearance plays. The study is interested in learning about how the participants understood their facial difference and how this has influenced their perception of themselves overtime. The study is keen to explore the positive experiences of growing up with a facial difference as well as some of the challenges.

# Why have I been approached?

You have been approached because you access support from an organisation that works with people who have a facial difference. If you identify as having a facial difference you may wish to participate in this study. The study requires information from people who have grown up with a facial difference and feel **comfortable** to share their experiences with other in a forum.

# Do I have to take part?

No. It’s completely up to you to decide whether or not you take part, even during the interview you have the option of opting out at any time. If you get to the stage of participating in the focus group or one – to -one interview and decide to take part and then change your mind, you have the right to do so without providing any reasons and without your rights being affected in any way. All research data collected until this point will be destroyed.

However, after the seven days of your participation in the interview or forum, you will no longer be able to withdraw as the data will be have been transcribed and used for analysis.

# What will I be asked to do if I take part?

If you decide you would like to take part, you will be invited to participate in a one – to- one interview. As the research facilitator, I will ask some questions about your experiences of growing up with a facial difference is in terms of your life chances, this may include, how you felt as you were growing up, how important you think appearance was as a child growing up, did you have support that was helpful, what positives were there. At the end there will be an opportunity for you to ask any questions.

You will have the option of choosing where the interview takes place for example in a comfortable and private room at a local voluntary organisation or over the phone and is expected to last between 30 minutes to an hour.

# Will my data be Identifiable?

All participants will be asked to create a fictious name for themselves to protect their identity and this will be used throughout the study. This will ensure the information you provide is anonymised and I can include a direct quotes from participants in my dissertation.

The research data collected for this study will be stored securely and only the researchers conducting this study and auditors will have access to these data:

* Audio recordings will be deleted once the project has been submitted for publication/examined
* The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
* At the end of the study, hard copies of consent forms (which contain personal sensitive data) will be destroyed.
* The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
* All your personal sensitive data will be confidential and will be kept separately from your interview responses (i.e. research data).
* There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.
* The information you provide will be anonymised and included in the data generated for this study and will be stored on an open access repository which can be accessed and used by other approved researchers to use. This is to assist further research and development in the area of facial difference.

**Data Protection and Transparency**

Manchester Metropolitan University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Manchester Metropolitan University will keep identifiable information about you [for up to 10 years].

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained (but will destroy the research data). To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting ethics@mmu.ac.uk.

As a university we use personally-identifiable information to conduct research and our legal basis for processing personal data is a ‘public task’. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research.  This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/).

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Our Data Protection Officer is Christopher Woolley (contact C.Woolley@mmu.ac.uk or legal@mmu.ac.uk).

# What will happen to the results?

The results will be summarised and reported in a dissertation and may be submitted for publication in an academic or professional journal.

# Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

# Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

# Who has reviewed the project?

This study has been reviewed and by the Department of Psychology Research Ethics Committee at Manchester Metropolitan University.

# Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Samina Kiran Tariq

Email: Samina.K.Tariq@stu.mmu.ac.uk

Department of Psychology │Manchester Metropolitan University │Manchester │M15 6GX

# Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr George Kountouriotis

Tel: +44 (0)161 247 2020│Email: g.kountouriotis@mmu.ac.uk

Department of Psychology │Manchester Metropolitan University │Manchester │M15 6GX

If you wish to speak to someone outside of the Department of Psychology, you may also contact:

Professor Car0l Haigh

Faculty Head of Ethics

Tel: +44 (0)161 247 5914 │Email: c.haigh@mmu.ac.uk

Faculty of Health, Psychology & Social Care │Manchester Metropolitan University │Manchester │M15 6GX

Thank you for taking the time to read this information sheet.

**Resources in the event of distress**

Should you feel distressed either as a direct result of taking part the following resources may be of assistance:

[NHS Choices](http://www.nhs.uk/) — 24 helpline for non-urgent medical advice
Helpline: 111

[Samaritans](http://www.samaritans.org/) — 24 hour helpline offering emotional support
Helpline: 116 123

[Changing Faces](https://www.changingfaces.org.uk/) – A charity for people and families who are living with conditions, marks or scars that affect their appearance.

\*Please see the [Changing Faces](https://www.changingfaces.org.uk/) website for a more extensive list of condition-specific support groups

# How to participate in this study?

If you would like to participate in the study please email Samina - Samina.K.Tariq@stu.mmu.ac.uk.

Many thanks.